

Online Support Groups for People with Dementia

ADI Conference

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Support and Advocacy: Of, by and for people with dementia

Online Support Groups for People with Dementia

- Self-help groups moderated by people with dementia and others – no caregivers
- Alternative to local support groups that don't meet their needs, or in absence of a local group
- Increasingly, people with dementia turning to social media to connect

Quote

The group has meant freedom to me....freedom to express my frustrations with this disease, freedom to express my fears about the future, freedom to be what I am on any given day with a compassionate group of people there to support me on dark days...whether by their humor, a virtual hug or quiet understanding.



Facebook Support Group

- Recognized the value to people with dementia of connecting with each other
- Provides opportunity for regular communication with immediate feedback
- Fills in gaps between in-person group meetings



Quote

This group has made me feel less alone, it's made me feel like I have a lot more living to do, people to help and jokes to tell. I have people I can share stories of memory loss to, people who will understand. We will all eventually forget each other as this disease progresses, but we have this moment now to feel comfort, solace and humor. Thank you!



Video Conferencing Support Group

- People with dementia were finding each other at webinars and connecting, creating community
- Created a sustained community using the same webinar software, of people living around the world



Quote

This group is of vital importance to me as, altho' I rarely post and I have other problems at present, here I have found firm friends with that essential understanding of problems, tactfully offered help and support, warmth, humor and patience, inspiring examples of coping and courage, and always someone there to respond when the way seems uphill and lonely. Thank you group!



Technology Used

- Requires a computer and Internet connection; for video support groups, also a webcam and microphone
- Make the Facebook group a “secret” group
- Zoom online meeting software, which we also use for webinars, online Memory Cafés, and interactive theatre projects



Quote

It's opened my eyes to the fact not only elderly people get dementia there are other people out there in their 40s and 50s and I'm not alone.



Format

- Free-flowing discussion
- Safe and respectful environment, where people with dementia can communicate without presence of caregivers
- Members of video group agree to “rules of participation”
- Facilitator training

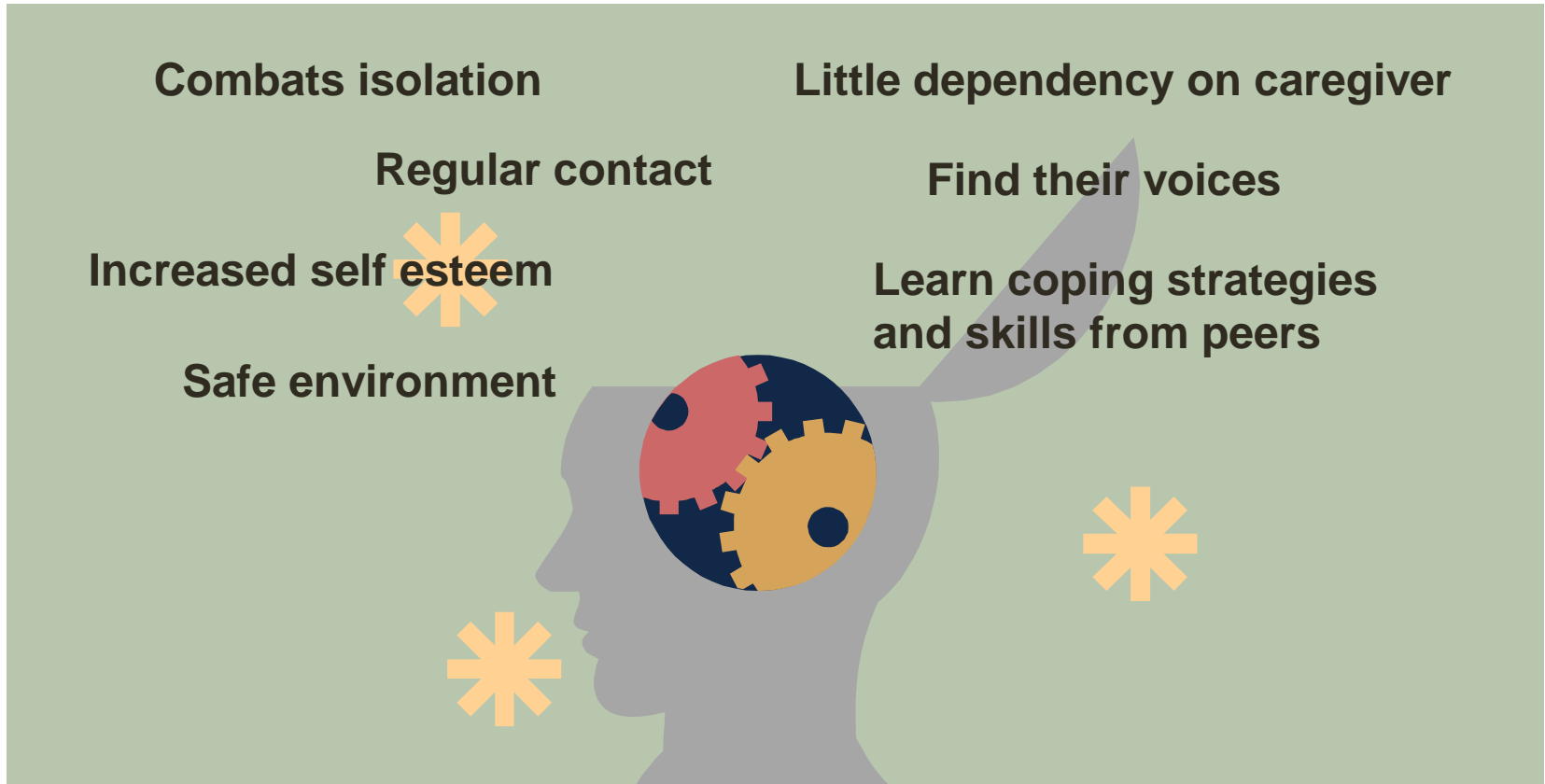


Quote

Talking to others like me is priceless. There is always someone here. Never have to worry about how am I going to get to the support group. When you really need to talk something out, it's here. Not in a week. Now. If you're having a bad day you can read or post the most garbled stuff and people get it. You never have to explain or apologize. And maybe most important, we are all treated as valid human beings here. Unlike most of the "normal" world.



Benefits to Participants



Quote

Dementia is a disease that that confines a person to a smaller world. Usually to your home. The online support group opens up the world while you are at home. Your little space becomes a vast community sharing thoughts and ideas. I see people all over the world, not only in the U.S., sharing the trials and tribulations of dementia. It is important that people with dementia ask each other for advice because we are the experts.



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Benefits to Organizations

Cost effective

Extend reach to people in isolated areas

Build capacity in people with dementia

No travel required for facilitators or participants

Provide volunteer opportunities to people with dementia



Uses technology most people already have



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Quote

*In the online community
you are treated as an adult.*



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Summary



The regular contact and friendships facilitated by online support groups, along with the power that comes with finding a voice in the support groups, has improved quality of life, built capacity for communicating, and increased self-worth when discovering that there are others who are dealing with the same issues.



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Quote

“Thank goodness for my virtual friends. Now that my old “friends” have abandoned me, my virtual friends are my best friends and I don’t know what I would do without them.”

